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ABSTRACT

The National Institute on Disability and Rehabilitation Research and the National Institute of Mental Health jointly sponsored a project for the development of statewide organizations for parents of children with emotional disorders. The Statewide Parent Organization Demonstration Project (SPODP) has two major goals: to stimulate and support the development of model statewide parent organizations that have the capacity to provide technical assistance, information, support, and networks to parents and parent organizations within states; and to evaluate the conceptualization, implementation, and outcome of these models to inform decision-makers about the most effective approaches in promoting such activity within states. The SPODP funded five extant parent organizations to develop statewide parent networks and organizational structures, in Hawaii, Minnesota, Montana, Virginia, and Wisconsin. This report describes development of the SPODP and examines the accomplishments of the organizations in the five states selected as demonstration sites. The description of each state's project is followed by a summary of quarterly data submitted by the project. The report concludes with results from a qualitative research study of the five parent organizations' goal attainment and issues and barriers impeding implementation of a statewide parent organization. Results suggest that local groups need 2-3 years and resources of approximately \$30,000 per year to establish a strong and well-functioning statewide parent organization. (JDD)

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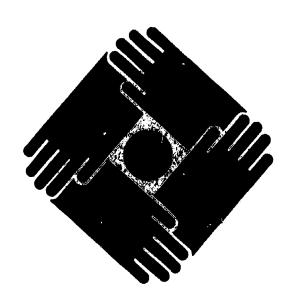


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STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT

FINAL REPORT



Research and Training Center on Family Support and Children's Mental Health
Portland State University

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STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT

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Introduction

The Statewide Parent Organization Demonstration Project exists as a result of the convergence of a number of influences. As the Families as Allies Conferences were held around the country, parents of children with emotional disorders were struggling to organize. In states with functioning parent support groups, this support was apparently an important service to parents. In states without parent support groups, parents were requesting this support in increasing numbers. It was also becoming clear that parents were an important source of input in efforts to improve service delivery. Parents who were not organized into a network were difficult to identify, inform or engage. Consequently, the National Institute or Disability and Rehabilitation Research and the National Institute of Mental Health jointly allocated \$100,000 to be awarded to states for the development of statewide parent organizations. The Research and Training Center on Family Support and Children's Mental Health served as the conduit for funding and provided technical assistance and evaluation services to the demonstration projects.

Purpose and Objectives

The Statewide Parent Organization Demonstration Project (SPODP) has two major goals: (1) to stimulate and support the develement of model statewide parent organizations that have the capacity to provide technical assistance, information, support, and networks to parents and parent organizations within states; and (2) to evaluate the conceptualization, implementation, and outcome of these models to inform decision-makers about the most effective approaches in promoting such activity within states.

Further, specific objectives were identified that each of the funded parent organizations were expected to meet. These objectives provided a framework for project evaluation. The objectives were stated as follows:

By the end of the project year, each Statewide Parent Organization will develop the following capacities:

- 1. a mechanism for inexpensive, accessible two-way communication with parents on a statewide basis;
- 2. a resource service for disseminating print and visual media accessible on a low cost basis to parents, professionals and parent groups statewide. If appropriate, an existing resource service may be expanded to include materials specifically relevant to parents of children with emotional disabilities; and,
- 3. support services, resources, information and visibility to develop and maintain ties with diverse groups and individuals throughout the state.

These capacities represent the essential framework within which the Statewide Parent Organizations provide the following services:

1. Referring parents to existing parent groups or to individual parents in their geographic area;



- 2. Directing parents to existing agencies able to answer questions and make referrals within the service delivery system;
- 3. Strengthening the network of parents and parent organizations by making a sustained effort to increase formal and informal contacts among individuals and groups;
- 4. Providing technical assistance and support to newly forming or ongoing parent support groups, including the latest information regarding services for emotional disturbances in children and adolescents and the range of community-based services to meet their needs;
- 5. Developing or enhancing a statewide parent organizational structure to provide information regarding pending legislation, state planning processes, and opportunities for public comment and testimony at relevant legislative and administrative hearings on a timely basis; and,
- 6. Providing special outreach to underserved groups of parents, such as low income parents, minority parents, etc.

The Statewide Parent Organization Demonstration Project is administered under the umbrella of the Families as Allies Project. Both projects focus on promoting the organization of parents of children with serious emotional disorders to give and receive support, acquire information about their children's conditions, and learn to advocate for their own children and for others.

Organized Project Activities

Between October 1988 and September 1989, the Statewide Parent Organization Demonstration Project funded five parent organizations to develop statewide parent networks and organizational structures. Existing parent organizations were eligible if their capacity to fulfill project objectives could be demonstrated. Potential applicants were recruited by sending an invitation to bid (See appendix) to each of the 215 parent organizations in the Parent Organization Directory and to an additional 75 organizations that had indicated an interest in being listed in the directory when it was updated. In addition, Child and Adolescent Service System Program (CASSP) and State Mental Health Representatives for Children and Youth (SMHRCY) personnel in each state were informed of this opportunity.

Forty-seven proposals were received from 38 states and the District of Columbia. Proposals were reviewed by a panel of national experts, a local panel of parents and professionals, and staff. Five states were chosen to receive \$20,000 each: Hawaii, Virginia, Wisconsin, Montana and Minnesota. The project leader from each of these states came to the Research and Training Center in November 1988 for two days of training and technical assistance.



During the following ten months, telephone contact was maintained between the Research and Training Center staff and parent organization staff. The group met again in March 1989 in conjunction with the spring CASSP directors' meeting. With this exception, the parent organizations were on their own in developing a statewide structure most compatible with their states' needs.

The amount of money in this contract was not sufficient to build a new parent network where none existed. States chosen to receive funds during 1988-89 had the specified capacities at least partially in place and were already engaged in some of the activities listed. The resources needed to be supplemented to carry out current activities and to ensure future existence of the statewide parent organization; at least part of each parent groups' efforts went into pursuing other sources of support (both monetary and in-kind).

Beginning in June 1989, the project evaluator made a site visit to each of the five parent organizations. The purpose of these visits was to observe the functioning of the statewide parent organization and collect data by interviewing the persons most involved in the organization's development.

Description of State Accomplishments

This section of the report examines the development of a statewide parent organization within each of the five states selected as a demonstration site. The situation varies according to the unique political and social conditions of the state. Several distinct approaches to the organization of parents have resulted. These unique models of organizational development will be explored along with the development and utilization of some of the services required in the contract. The description of each state project is followed by a summary of the quarterly data submitted by the project. Although different titles were used in each state, the person paid from grant funds or primarily responsible for the grant is referred to as the "project director."

HAWAII

Hawaii Families As Allies is a statewide parent organization which is not affiliated with any umbrella disability organization, and began as a parent support movement with a conference held in December 1986. The original conference was jointly sponsored by the Mental Health Association, the Children's Mental Health Services Branch of the State Department of Health, the Office of United Self-Help, and the Hawaii CASSP office. A staff member from Hawaii CASSP was instrumental in facilitating the development of the first support groups and in writing the grant that resulted in Hawaii Families As Allies becoming one of the five demonstration sites. This staff person served as project director for the Hawaii Families As Allies development effort; she recognized that her job was to help parents develop the statewide organization and then retire.

The Hawaii Association for Children and Adults with Learning Disabilities (HACLD) was the fiscal agent for this project. HACLD has provided Public Law 94-142 training and technical assistance to parents of children with emotional disorders on each island. The project director from Hawaii Families as Allies coordinated the fifty-hour training session on each of the neighboring islands, referred parents to the training and assisted parents in developing a "buddy system" after they were trained. This



"mentoring" method of assistance is considered particularly appropriate within the Native Hawaiian culture. Trained parents provided support to other parents in the form of advocacy assistance, emergency respite, transportation, referrals to appropriate agencies, information specific to certain problems, and supportive listening. These parent leaders received ongoing training through the Parent Leadership Training, which was designed and presented by the staff person from Hawaii CASSP to prepare parents for leadership in the statewide organization. The training was renamed Parent Empowerment Training and currently is conducted by the leaders of the Hawaii Families As Allies.

As a part of her CASSP activities, the project director recruited a parent to serve as county coordinator on each of the islands or major geographic areas. These county coordinators were paid a small stipend and required to make regular reports regarding their work with other parents. Each county coordinator was in regular telephone contact with the project director. At the beginning of the demonstration project, there were two formal support groups for parents of children with emotional disorders in Hawaii. Although county coordinators attempted to develop support groups in their areas, support groups were not appropriate mechanisms in some areas or for some groups. In these areas, informal support networks seemed most functional. On Maui, parents meet regularly in a support group called Parents Alliance for Caring Education (PACE). A group of parents continues to meet on Oahu and a small support group meets in urban Honolulu. Molokai parents meet regularly (Molokai Families As Allies) and have developed a brochure and information packet for parents. Overall, five support groups are meeting on a regular basis and involve about 25 parents.

The primary objective of Hawaii Families As Allies is to develop a support system that responds to the needs of families on state and local levels. The officens of the organization made a specific choice to focus on developing supportive networks and to postpone system advocacy movements until the organization became firmly established. Toward the end of the grant, the organization did participate in developing family support legislation. Individual parents have also been involved in system advocacy as committee members.

The momentum of this project was slowed by two separate incidents. In April, the project director was in a serious car accident and was minimally involved for most of the rest of the year. Although she was beginning to transfer leadership to parents at the time of the accident, her absence meant that some planned activities had to be forgone. The second incident involved a financial management error which forced Hawaii CASSP to end in June rather than the end of September. Hawaii CASSP provided the project director's salary and covered much of her travel expenses. At the time that the project director was ready to return to work from her accident, CASSP ended and she had to seek other employment. The momentum of parent organizing has not resumed after these two incidents.

Currently, a small core of parents provide the leadership for Hawaii Families as Allies. The president and president-elect have been active in the organization from the beginning and continue to be crucial to the life of the organization. The officers of the organization continue to offer the Parent Empowerment Training to parents from all over the state. The organization has a solid reputation with state agencies and human service providers, thereby providing a voice for parents at the state level. At this point, the organization has no paid staff or office. Funding for the organization is an ongoing issue and no new funding has been obtained.



Hawaii Families as Allies

	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
-	1a. # of telephone contacts by geographical area	1a. Kauai-19, Maui-20, Oahu-8, Molokai-17 Hilo-9, Kona-10, State Office-78, (total = 161)	1a. Kauai-40, Maui-25 Oahu-25, Molokai-19 Hilo 25, Kona-10, State Office-122, (total=266)	1a. Kauai-35, Maui-17 Ohau-24, Molokai-40 Hilo-10, Kona-7, State Office-50, (total = 183)	1a. No data available
Capacity	b. # of face-to-face contacts by area	b. Kauai-8, Maui-11, Oahu-15, Molokai-42, Hilo-5, Kona-12, State Office-57, (total=150)	b. Kauai-31, Maui-95, Oahu-97, Molokai-149, Hilo-87, Kona-80, State Office-139, (total=688)	b. Kauai-44, Maui-29, Oahu-214, Molokai-227 Hilo-75, Kona-4, State Office-47, (total = 640)	b. No data available
Ca	c. # of contacts by letter for each area	c. Kauai-1, Maui-0, Oahu-0, Molokai-3, Hilo-0, Kona-2, State Office-382, (total=388)	c. Kauai-83, Maui-375, Oahu-50, Molokai-50, Hilo-75, Kona-120, State Office-1215, (total = 1878)	c. Kauai-2, Maui-3, Oahu-50, Molokai-75, Hilo-2, Kona-2, State Office-127, (total = 261)	c. No data available
7	1. # cf names on the Family-to-Family newsletter mailing list	1. 350	1. No data	1. No data	1. No data (Sept. only)
city	2. # of items acquired by the resource library	2. 62	2. 4	2. 2	2. No data (Sept. only)
Capac	3. '# of items requested by area	3. Kauai-3, Maui-4 Molokai-2, (total=9)	3. Kauai-1, Maui-1, Oahu-2, Kona-3, (total = 7)	3. Kauai-1, Maui-2, Oahu-1, Molokai-1, State Office-5, (total = 10)	3: No data (Sept. only)
ty 3	1. # of educational forums or activities by area	1. Molokai-20, State Office-23, (total = 43)	1. Kauai-28, Maui-45, Oahu-26, Molokai-20, Hilo-7, Kona-4, State	1. Oahu-14, Molokai-17, Itilo-7, State Office-35, (total = 73)	1. Maui2
Capaci	 Media monitoring and utilization # of statewide or national conferences, meetings and trainings attended by affiliates 	2. Plans still being developed3. 11 (at least)	Office-62, (total = 192) 2. No data 3. 7 (at least)	2. No data 3. No data	2. No data 3. 9 (at least)



Hawaii	page	2
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	Evaluation Indicators	Ouarter 1	Ouarter 2	Quarter 3	Ouarter 4
Service 1	1. # of referrals by area (referrals made were not categorized into support groups or I&R services)	1. Oahu-2, Kona-2, State Office-5, (total=9)	1. Maui-7, Oahu-8, Molokai-10, Hilo-5, Kona-3, State Office-20 (total = 53)	1. Hilo-15, State Office-10 (total = 25)	1. No data
	Coordination of a statewide family conference	In progress-scheduled for April 8, 1989	1. Conference held; 800 brochures distributed to publicize the conference; 45 schotarships provided to case transportation costs; 69 individuals attended; parents from each county attended	1. Not applicable	1. Not applicable
ice 2	2a. # of trainings held, attended by representatives from each geographical area	2a. 18 (at least)		2a. Not specified	2a. 3
Service	b. Nature of trainings	b. County Coordinator orientations; C.C. retreat; Parent Leadership Training Institutes sponsored by CASSP; November, 1988 FAA meeting to prioritize program needs of families: legislative workshops (advocacy focused)	b. Parent Leadership Training Sessions; County Coordinator retreats; March Hawaii FAA workshop with the Exec. Director of the National Association of Child Advocates; Hawaii FAA "Parents as Professionals" conference	b. Not specified	b. Parent Empowerment Training session; presentation on cross-cultural issues; technical assistance provided to the Child and Adolescent Mental Health Div. of the Dept. of Health
8	1. # of support-oriented contacts made with each area	 Kauai-3, Maui-8, Oahu-20 Molokai-30, Hilo-2, State Office-61, (total = 124) 	1. Kauai-40, Maui-107, Oahu- 77, Molokai-141, Hilo-85, Kona-80, State Office-132 (total = 660)	 Kauai-56, Maui-39, Oahu- 224, Molokai-237, Hilo-30, Kona-5, State Office-35, (total = 626) 	1. Not specified by areaofficers maintained weekly phone contect and met twice this quarter
vice	2. # of advocacy-oriented contacts made with each area	2. Maui-3, Kona-5, State Office-61, (total=69)		2. Maui-2, Hilo-25, Kona-5, State Office-17, (total = 49)	2. At least 6 contacts (not specified by areas)
Ser	3. # of contacts made to supply general information by area	3. Kauai-25, Maui-20, Oahu-1, Molokai-12, Hilo-12, Kona- 17, State Office-418, (total = 505)	3. Kauai-87, Maui-330, Oahu 53, Molokai-45, Hilo-85, Kona-127, State Office- 1219, (total=1966)	3. Kauai-25, Maui-7, Oahu-50, Molokai-88, Hilo-10, Kona-3, State Office-127, (total = 310)	3. No data



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	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ovarter 4
Service 4	1. Nature of legislative activities	1. Sponsorship of parent participants in legislative workshops on each island; Hawaii FAA will obtain a box at the State Capitol to receive all info about bills, agendas, meetings	1. Parent Leadership Training Sessions (Hawaii CASSP sponsored); March Hawaii FAA workshop; Hawaii FAA will assume responsibility for the Hawaii CASSP Parent Leadership Training Program in June	1. No data	L. Met with lobbyist from MHA-Hawaii; working on family support package with State. Rep Dennis Arakaki; discussions in the Governor's office, Developmental Disabilities Coordinating Council, and Hawaii Advocates for
	2. Media monitoring and utilization	2. Plans still being developed	2. No data	2. No data	Children and Youth 2. No data
Service 5	Development of family support networks appropriate to specific cultural groups	Application of a personal approach-encouraging, developing and maintaining friendships with all parents that are contacted	1. Same as Quarter 1	1. Same as Quarter 1	1. Same as Quarter 1 plus parents attended a workshop on cross-cultural issues on Maui



MINNESOTA

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The statewide parent organization demonstration project in Minnesota was affiliated with Parent Advocacy Coalition for Educational Rights (PACER). PACER was a natural focal agency since it is a statewide organization providing information, training and assistance to parents of children and youth with all disabilities. As a nonprofit, tax-exempt corporation, PACER is operated by a board of directors representing each of the seventeen consumer groups and at-large members who are parents of minority children. PACER's philosophy is "parents helping parents." The majority of the board members and staff are parents of children with disabilities. The original intent of the demonstration project was to develop a separate organization of parents of children with emotional disorders that would become an ongoing member of the PACER coalition of parent groups. To this end, an advisory board of parents was identified and met several times during the grant year. However, this group of parents did not have the energy or interest needed to begin a new organization.

The demonstration project grant allowed PACER to hire a half-time staff member to serve as project director. This person has been on staff at PACER for some time and has enjoyed the benefits of being associated with the organization. The project director has an office at PACER and uses their conference rooms and resource library. Telephone calls from parents of children with emotional disorders are received through PACER's toll free 800 number and referred to the project director. She responds to these calls with the help of other PACER staff, who also serve as backup when she is out of the office.

Development of support groups has not been a high priority in this state. There were several mixed disability support groups in the state prior to the demonstration grant; seven support groups are currently available to parents of children or adolescents with emotional disorders. Two groups are in the Twin Cities metropolitan area and five are in other parts of the state. The number of requests for referrals continues to outpace the development of groups, with many inquiries made on behalf of parents by hospitals and mental health professionals. The project director has established and maintained a support group for parents in Minneapolis.

Legislative advocacy and system change have been among the primary activities of the project director in this state. She has attended a large number of meetings with other organizations, coalitions and advocacy groups to disseminate information about the demonstration project to professionals who work with families. She has also provided a parent voice in these meetings and in efforts to change the system of care. Advocacy for passage of children's mental health legislation required much of her time. Many parents in Minnesota have indicated an interest in being involved in children's mental health legislation and many of these activities are anticipated to continue.

Currently, PACER is seeking funding to continue the project director's part-time position to focus solely on support for parents of children with emotional disorders. Without continued funding, PACER will respond to calls from these parents in the same way as calls from parents of children with other disabilities. The efforts to organize a statewide parent organization continue, although strong leadership has not yet emerged.

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Minnesota	PACER
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	Mindesota PACER					
	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4	
	1a. # of calls to 800 number b. Services requested	1a. 112 b. No data	1a. 277 b. Information & assistance	la. 317	1a. 400	
	b. Services requested	o. No data	0. Information & assistance	b. Info re: EBD, available services, access to services	b. No uz s	
	c. Information/referrals provided	c. No data	c. Same as 1b	c. Same as 1b	c. No data	
,	d. Nature of technical assistance and resources provided	d. No data	d. Requests from policy makers & others to attend meetings	d. No data	d. No data	
Capacity	2a. How parents learned about PACER, EBD project	2a. Newsletter, brochure, presentations	2a. PACER brochure and newsletter mailed to parents, child-serving agencies; 1 pg. description of EBD project distributed at workshops, hearings	2a. Brochures, newsletters, news releases	2a. Staff presentations, project brochure and all other EBD project & PACER materials	
	b. # of new names on brochure mailing list	ხ. 0	b. 0	b. No data	b. No data	
	3a. 3 Advocacy workshops	3a. None held this Quarter	3a. 2		Ba. 2	
	b. Participant evaluations	b. Not applicable	b. 60	b. 45	b. 1500 (parent surveys)	
	4. # of walk-in contacts	4. 1	4. 3	4. 0	4. 0	
Capacity 2	 # of resource requests Type of information requested 	1. 0 2. N/A	 200 A Guidebook for Parents of Children with Emotional Disorders 	1/2. 230 Guidebook for Parents; 14 Taking Charge; 23 Ombudsman brochures	1/2. 76 Guidebook for Parents; 2 Taking Charge; 31 Ombudsman brochures; 27 A.D.D. & Medication; 18 Why Can't My Child	
S	2. # of new equipitions	2			Pay Attention	
	3. # of new acquisitions	3. 3	3. 2	3. 5.	3. 6	
	1. # of contacts with other groups and organizations	1. 7	1. 19	1. 13 meetings plus eight workshops	1. 14 meetings plus two workshops	
	2. # of times Telephone Tree was initiated	2. No data	2. No data	2. No data	2. No data	
ty 3	3a. # of requests for Pacesetter articles on EBD	3a. No data	3a. No data	Ba. Articles in MN Dept. of Ed. newsletter and MN Edu- cators of the Emotionally Disturbed newsletter	3a. No data	
#Cİ	b. # of new names on EBD mailing list	b. 90	b. 480	b. 420	b. 420	
Capacity	c. # of newsletters distributed	c. 25,700 (Pacesetter)	c. 323 (Advocate)	c. 27,000+ Pacesetter (1600 to people involved with children with EBD); 325 Advocate	c. 28,000 Pacesetter	
	4a. # of brochures distributed	4a. 0	4a. 0		4a. 1,200 (EBD project)	
	b. # of EBD project fliers distributed	b. Not yet developed	b. 400	b. 3000	b. Same as 4a.?	
	<u> </u>	 		<u> </u>		



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	Minnesota pg. 2						
	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4		
	1a. # of parent requests for referral to other individual parents	1a. 5	1a. 17	1a. 42	1a. 91		
	b. # of parents referred to individual parents	b. 0	b. 6	b. 19	b. 50		
Service	c. # of parents referred to parent groups 2. Type of I/R issues	c. 2 2. Low # of requests for referral due to historic unavailability of support groups	c. 8 2. Increased # of requests due to increased awareness re: EBD project; need to maintain parent-to-parent support network	c. 21 2. Support groups overloaded with referrals; 4 other communities request technical assistance with forming new support groups	c. 45 2. Many inquiries made on behalf of parents by hospitals and mental health professionals		
	3. Follow-up survey sent to parents	3. Survey not yet developed	3. Results of survey need to be tabulated and analyzed	3. Results show parents want/need support groups	3. 1364 surveys mailed, 200 returned; see Service 3, #4		
7	 # of requests for I/R # of parents referred to I/R services Nature of requests 	 50 12 Assistance with resolving 	1. 175 2. 23 3. Same as Quarter 1	1. 190 2. 2 3. Assistance with resolving	 1. 163 2. 2 3. Same as Quarter 3 plus 		
Service		school issues; referrals for evaluation, county services, and counseling	•	school issues; legal assistance with resolving complaints re: service agencies and insurance companies; referrals to county services			
	1a. # of staff contacts with parent groups b. Nature of contacts	1a. 2 b. Legislative updates; assistance with services	1a. 5 b. Same as Quarter 1	la.9 b. Educational assistance; referral to community resources	la. 7 b. Educational assistance, organizing a group, community resources		
ice 3	2. # of meetings with representatives from parent groups	2. 1	2. 2	2. 2	2. 2		
Serv	• •	3. 0	3. 2	3. 2	3. 1		
	4. Assessment (survey) of what parents want/need re: self-help groups	4. Survey not yet sent	4. Results from over 400 respondents not yet tabulated or analyzed	4. Results used to facilitate additional parent-to-parent group connections and referrals	4. Extensive data on page 5 of 4th Quarterly report		
4	2. # of requests for information re:	1. 0 2. 0	1. 2 2. 18	1. 4 2. 12	1. 2 2. 27		
Servic	starting a new group 3. # of times technical assistance provided	3. 0	3. 2 workshops (55 people indicated interest)	3. T.A. provided thru an unspecified # of ????	3. T.A. provided thru an unde- termined # of phone contacts and mailings		
				 			



	Minnesota pg. 3					
	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Quarter 4	
	1. # of meetings re: development of a statewide parent organization	1. 6	1. 5	1. 6	1. 4	
	2. # of meetings re: pending legislation or legislative agendas	2. 10	2. 12	2. No data	2. 0	
	3. # of calls to parents re: legislative agendas		4	A	3. 0	
'n	4a. Telephone tree	4a. Not yet in place	4a. 40 member Telephone tree in place	ale: t parents of opportunities to serve on county service	4a. No data	
Service	b. Other project activities related to legislative issues	b. 950 fliers sent to parents and professionals informing them of Public Hearings sponsored by the Sub- committee on Children's Mental Health	b. Parents and/or staff members testified at MN House & Senate Hearings as well as at Governor's Hearings on Children's Mental Health; 36 letters from parents supported children's legislation	advisory councils b. Focus was on implementation of new legislation and parent involvement in implementation activities	b. Results from parent surveys show that parents are strongly interested in being involved in legislative activities; PACER plans to use this info in planning future services	
	Staffings attended with low income or minority parents	1. 5	1. 8	1. 14	1. 7	
	* •	2. 4	2. 19	2. 27	2. 26	
Service 6	3. Focus of contacts	Individual advocacy and facilitation of parent involvement	3. Outreach to Indian reserva- tions; school related issues (i.e., truancy, suspension, expulsion, labeling of Indian children in public schools)	3. Emphasis on culturally competent materials used in workshops and inclusion of minority parents in workshop planning and facilitation	3. Same as Quarter 3 plus seeking to recruit minority advisory board members and participating with MEED and MNCCBD on their minority initiatives	
	4. Minority parents' evaluations of their involvement with EBD project	4. No data	4. No data		4. No data	
	5. # of translated brochures given to refugees	5. No data	5. No data	5. No data	5. No data	



MONTANA

The statewide parent demonstration project in Montana was affiliated with Parents, Let's Unite for Kids (PLUK), which is a statewide network for parents of children with disabilities and chronic health problems. PLUK also serves as a core organization for advocating changes in Montana's human service delivery system. Because Montana has a small and rural population, a separate statewide organization for parents of children with emotional disorders was thought unfeasible. The intent of the demonstration project was to develop a greater awareness in the state of the problems of parents of children with emotional disorders and to increase PLUK's ability to represent and respond to these parents' needs. Therefore, this demonstration project's primary objectives involved locating, contacting, and providing support to parents. The project director was hired on a part-time basis to organize support services for parents of children with emotional disorders. She has space at the PLUK office and uses their telephone line and resource library.

Because of the rural geography of Montana, mixed disability support groups are most feasible. Twenty of these groups existed prior to the demonstration project. Twenty-one support groups were functioning at the end of the project year; two were primarily for parents of children with emotional disabilities and nineteen were mixed disability groups. In addition, thirteen parents from around the state have agreed to be Pilot Parents, who provide support when support groups are not available or appropriate. Brochures and posters publicizing the toll-free number were successful in increasing contact with parents. The project director spent much of her time in case advocacy, working with local support groups and community leaders to raise public awareness about the needs of children with emotional disorders.

PLUK is involved integrally in system advocacy in Montana. During the past year, legislation related to children's mental health was passed, partially due to the efforts of PLUK staff and parents. The project coordinator has been appointed to the State Advisory Council for Mental Health, which has considerable influence in funding for mental health services. The concept of including a consumer representative as a voting member was entirely new to the council; there was considerable resistance to her inclusion, but good support from the state-level director.

The major expenses for sustaining a statewide parent network are staff salaries, long distance telephone, and travel. Because of the great distances in Montana, travel money is an important and expensive budget item. During the last quarter of the grant, the commuter airline in Montana went bankrupt and instate travel was only possible on major airlines, which further added to the travel expense. PLUK has been successful in generating new grant funds to continue the salary of the project director.



Montana PLUK

	Evaluation Indicators	Quarter 1	Ouarter 2	Ouarter 3	Ouarter 4
Capacity 1	b. Other information about callers	1a. 21b. Parents of children with emotional disabilities2. No data	b. 55 mothers; 4 fathers 3 social workers	b. 54 mothers; 9 fathers; 2 M.D.'s; 5 social workers 5 school personnel	1a. 135 b. 102 mothers; 2 fathers; b. 31 providers 2. 22 (some duplicates)
Capacity 2	 # of new acquisitions for the resource library # of requests for resources Types of resources requested Who made requests 	 Not specified Not specified Computer searches for research articles Parents 	1. 4 2a. 30 b. Taking Charge; other handbooks c. Parents	2a. 39 (filled); 8 (delayed)	1. 0 2a. 8-10 each week b. Start-up materials c. Parents
Capacity 3	 1a. # of newsletter issues b. # of newsletters distributed 2a. # of brochures available b. # of workshops held b. Topics of workshops c. # of participants d. Participant evaluations 4a. # of meetings with other groups in state b. With whom 	1a. 1 b. No data 2a. Not specified b. 3000 3a. None-plans are in action for several spring workshops b. Not applicable c. Not applicable d. Not applicable 4a. No data b. No data	b. 1600 2a. 62 b. 2900 3a. 4	b. 1600 (plus 58 new names)	c. 80 total d. Positive comments and high ratings 4a. 4



		•	Montana pg. 2		
ı	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
Service 1	 # of requests for referral # of parents referred to parent groups # of links made between individual parents 	 No data 7 (at least) 10 	2. 22	 No data No data 13 	1. 10 2. 3 3. 20
8	1. # of requests for info. and/ or referral	1. No data	248 (some are duplicated requests)	1. 112	1. 137
Service	2a. # of parents referred to I&R services b. Types of services parents are referred to	2a. No data b. No data	2a. 237 b. School district or special education; mental health centers; Montana Advocacy Program; private therapists; state facilities and agencies	2a. 0 (these parents sought only info) b. Not applicable	2a. N/A (PLUK is the I/R Service for MT b. Counseling services, school tutors, A/D treatment school services, crisis calls, insurance or medicaid info
Ice 3	Successful strategies for strengthening the network of parents and parent organizations	1. Informal meetings between PLUK's Community Trainer and parents to establish rapport; phone calls are followed up with supportive letters; Christmas cards sent to parents	1. Having one format for all groups; keeping parents' organizational responsibilities to a minimum; providing ongoing support & info sharing at meetings; establishing a reputation for efficacy	1. Allowing groups to form agendas; PLUK pasent support group meets twice monthly; a group of core parents provides the structure and stability needed by new parents	1. Same as Quarter 3
Service	2. Unsuccessful strategies	2. No data	2. Advertising a meeting before establishing a local reputation; allowing mental health professionals to attend meetings	2. The lack of a committed core group of parents in Lewiston has prevented the survival of a parent group there	2. Same as Quarter 3
Service 4	 # of requests for technical assistance # of requests for info about starting a new group 	1. No data 2. No data	 1. 12 2. 5 from agencies; 4 from parents 	1. None 2. None	1. 0 2. 0



Montana pg. 3

	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
Service 5	1. # of organizational members statewide 2. Nature of legislative activities	1. No data 2. Parent/newpaper columnist to do regular articles; Parent Agenda (increased insurance coverage for mental health services, expanded slots for adult supported work, case management as Medicaid reimbursement, data collection system within the family Service Agency); PLUK is linked with the mental health lobbyist	1. 1600 2. Parent Agenda (insurance coverage and data collection are likely to succeed);efforts to get a "sympathetic" legislator appointed to head the state PIC Council were successful; educating the Montana legislature	1. Same as Quarter 2 2. Same as Quarter 2	1. No data 2. Continue educating local legislators, encouraging the Dept. of Institutions to maintain its current family approach
Service 6	Activities to provide outreach to underserved parents	1. PLUK's Community Trainer made 2 visits to the Crow Reservation, using her contacts with the Catholic church	1. Providing 4 workshops in the Salish-Kootenai Reservation dealing with legal issues & special education services; a counselor is providing weekly parent support services to Crow Reservation parents; providing highly personalized assistance to individual families	Outreach to parents living on the Crow Reservation continues	1. Meeting with the Home/ School Coordinators, planning workshops in Browning, Pablo, and Crow Agency



WISCONSIN

Wisconsin Family Ties (WFT) is a statewide network composed of a number of active parent support groups, varying between 9 and 14 groups throughout the year. Early development of the organization was supported by a CASSP grant administered through the Alliance for the Mentally III of Wisconsin; as a result of these development efforts, Wisconsin Family Ties was established in June 1987 with eight local affiliates.

WFT encourages participation in its activities by local affiliates and their members and other concerned individuals. The WFT Board of Directors is composed of seven parents of youth with emotional, behavioral or related disorders. The board of directors includes a president, vice-president, secretary, treasurer, newsletter editor, liaison from AMI of Wisconsin, and an executive director.

The demonstration grant allowed for one part-time paid staff member. WFT has an office in the same building as Wisconsin Coalition for Advocacy, which served as the fiscal agent for the demonstration grant. The WFT project director is able to use their copy machine, clerical support services, and accountant on a cost reimbursement basis.

During the grant year, Wisconsin Family Ties participated in a pooled toll-free telephone line. The number of long distance calls has increased over the year, with about 80 calls in the third quarter. WFT has maintained a resource service and has continued to add print and video materials over the year. Many of the telephone calls and requests for information and materials have been from professionals.

During the year, WFT conducted five regional conferences, which were organized by the board of directors and utilized local professionals and a state legislator. The conferences were to reach otherwise unidentified parents of children with emotional disorders and introduce them to professionals and services available in the local area. Inquiries about starting new support groups have come from participants in the regional conferences.

Wisconsin Family Ties has been very active politically and members of the board of directors maintain ties with a number of coalitions and advocacy groups. As WFT has become more visible, more requests have been made for parent input in policy making at all levels statewide. WFT parents also helped pass the "Children Come First" legislation, which will fund community-based services, case management and interagency coordination in four counties.

The project director wrote three small grant applications during the year, two of which were funded. WFT continued to receive support from CASSP funds until January 1990; \$5,000 is still available from the demonstration project. WFT's budget consists of these funding sources, some CASSP evaluation funds, and private donations. The executive director and board will be writing more grants for continued funding. WFT is incorporated as a private, nonprofit organization.



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Wisconsin Family Ties

	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
Capacity 1	 Telephone intake form to be developed # of telephone calls (incl. 800#) Info about callers 	earlier report) 2a. 41		2a. 110	1. Same as Quarter 1 2a. 93 b. 48 parents; 45 professionals
Capacity 2	 # of new resource acquisitions # of requests for resources Nature of requests 	 295 118 Mostly written resources 	 6 20 Lists of resources, pamphlets, handbooks 	 26 23 Manuals, lists of resources, newsletters 	1. 8 2. 15 3. Lists of resources, brochures, articles, news- letters, info on legislation
apacity 3	b. # of returned brochure forms	1. 2,830 2. 226 3a. 899 b. 18 4a. 0 b. Not applicable	 200 118 480 19 2 Legislative activities, advocacy, working w/the system, info about various disorders, CASSP 	b. 22	1. 2664 2. 351 (End total = 2404) 3a. 473 b. 10 4a. 0 b. N/A
S	 c. # of participants 5. # of meetings w/other groups in the state 6. Requests for speakers 	c. N/A 5. 23 6. Not counted	c. 113 (total) 5. 24 5. 4		c. N/A 5. 23 5. 6





Wisconsin pg. 2

Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
1. # of parent requests for referral 2. # of parents referred to parent groups 3. # of parents referred to individual parents		1. 18 2. 15 3. N/A	2. 17	1. 9 2. 8 3. N/A
1. # of I/R requests 2. # of parents referred to I/R services	1. 12 2. 9	1. 25 2. 23		1. 17 2. 12
from parent groups	1. 3 2. 7			1. 3 2. 12
1. # of requests for technical assistance 2. Type of technical assistance provided 3. # of requests for info about starting new groups	1. 6 2. General start-up info, "maintenance fund" money, providing meeting speakers 3. 3	 4 Printed resources, copying, purchased a tape recorder, funding provided for special projects, general written correspondence 7 	 8 Financial assistance, general start-up info 8 	1. 10 2. Support for ongoing & new groups, fundraising 3. 5
1. # of legislative activities 2. Nature of activities	1. 2 2. Maggie M. met w/WCA staff, attorney, and author of "The Children Come First"; a summary of this legislation was given to affiliate group leaders	1. Numerous 2. Educational forums, parent testimony, parent presen- tations to numerous task forces, workshops, meetings	1. Same as Quarter 2 2. Educational forums, mailed legislative alerts, calls to legislators urging acceptance of "The Children Come First", letters sent to the governor urging him not to veto this passed legislation local committee formed to research design of technical college course on respite care for children with emotional disorders	1. 6 2. Wisconsin Difference Coalition invited State Rep. Young to speak at WFT's Oct. conference, WFT newsletter reported news on the "Children Come First" proposal, advocating passage of Proposal 4, committee meeting to develop a continuing ed. course for caretakers of children with emotional disorders, ongoing meetings with Rep. Young



Wisconsin pg. 3									
Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4					
1. Nature of efforts to reach underserved parents	1. Multi-agency meeting to occur in mid-January to pursue the development of a support group for black parents in the Milwaukee area. The 800# provides for those unable to pay for calls.	1. Meeting held in Quarter 1 has not yet yeilded results; Head Start parents and staff became involved in publicity efforts for WFT regional conferences. 800# continues to provide access.	1. Low income parents received scholarships and expense reimbursements to attend regional conferences. 800# continues to provide access.	1. Same as Quarter 3. 800# continues to provide access.					



VIRGINIA

Parents and Children Coping Together (PACCT) grew out of a local parent support group in the Richmond, Virginia area and was incorporated in May 1986. The corporation was formed as a private nonprofit organization to provide services to parents of children and adolescents with severe emotional disabilities and mental health problems; these services include education, resource information, support, and advocacy.

As a result of the statewide parent organization demonstration grant, a part-time project director was employed to coordinate supportive services for parents and children. The project director reported to the PACCT Board and became a member of the Board at the end of the grant. PACCT has courtesy office space with the Mental Health Association. The Virginia Treatment Center for Children originally provided space for the resource library, which was moved to the PACCT office toward the end of the grant period.

PACCT was delayed in beginning demonstration grant activities because the nonprofit incorporation had to be completed. Once this process was finished, PACCT was able to avoid working through a fiscal agent. Grant funds were received by PACCT in December 1988 and a project director was hired in January 1989. PACCT chose not to install a toll-free telephone line and encouraged parents to call collect on their regular phone line. The number of phone calls progressed over the year, with a peak of 65 in the fourth quarter. The newsletter has also functioned as a mechanism for communication.

Five parent support groups were affiliated with PACCT at the beginning of the demonstration project; PACCT had nineteen affiliates at the end of the year. Some of these affiliates were existing groups identified and aligned with PACCT by the project director. Other groups developed over the year.

The project director and other members of the Executive Committee developed two workshops that can be conducted upon request. One workshop is for professionals and involves a panel of four parents who describe their family, their child and the effects of having a child with emotional disabilities. The parents also speak about their experiences with the service delivery system. This workshop has been presented to professionals who work for the Virginia Department of Mental Health, Mental Retardation and Substance Abuse.

The second workshop was developed for parents and focuses on parent support groups, parental rights, the mental health system, the educational system, and advocacy. Both workshops will be presented at conferences around the state.

The project director left PACCT at the end of September 1989 to assume another job. A new project director was hired and Virginia CASSP agreed to fund the position for the next two years. Some funds are available from the demonstration grant to provide PACCT with a small operating budget.



Evaluation Indicators Ouarter 1 Ouarter 4 Ouarter 2 Quarter 3 1a. # of parents added to newsletter la. 30 la. 170 1a. 354 la. # of new names unknown: mailing list sent 1790 newsletters b. "Letter to the Editor" b. No data b. Announced in April newsb. Lack of parent response-letter, request parent input may be due to parents' need of immediate answers c. Articles written and submitted by c. No data c. Several written by parents c. No data c. Several articles Virginia parent support groups 2a. # of incoming calls 2a. 6 (at Parent Resource Ctr.) 2a. 21 (PRC); 30 (PACCT) 2a. 49 2a. 65 b. How caller learned of # b. No data b. No specific data b. No data b. No data c. Type of information requested c. Referrals and resource c. One-to-one support, assisc. Same as Quarter 2 c. General info & assistance: materials tance with mental health resources, technical or school systems, technical assistance, referral to assistance, grant & referral parent groups info., support groups d. Type of referral made d. System not in place d. Refer parents to existing d. Same as Quarter 2 d. Same as Quarter 2 support groups, agencies, services 1a. # of resource center contacts lla. 6 lia. 23 l1a. 10 lla. No data b. Type of information requested b. Video materials b. Videos, books, bibliograb. Videos b. Printed resources, videos phies, info on PACCT support groups, resource center, newsletter c. # of material distributions c. Not clear (see pg. 2) c. No data c. No data c. Numerous d. # of each type of Resource Ctr. d. No data d. No data d. No data d. No data materials by geographic region e. # of new acquisitions e. 50 e. 1 (plus 50 copies of Taking e. 52 e. 6 Charge purchased) 2. # of materials requested Same as 1a. 2. Same as 1a. 2. Same as 1a. 2. Same as 1a. 3a. # of suggestions from newsletter Ba. No data Ba. No data Ba. No data Ba. Parents have not requested purchase of new materials b. # of Resource Ctr. requests which b. N/A b. N/A b. N/A b. N/A cannot be addressed and why 1a. Copy of brochure for statewide parent 1a. Not yet developed 1a. Developed in March la. Developed in March ha. Same as Quarter 2 organization ь. 0 b. # of materials distributed Ь. 200 b. 2000 b. 2000 2a. # of staff visits to local support groups 2a.0 2a. 8 (at least) 2a. 12 (at least) 2a. 3 39 b. # of meetings and contacts with other b. 2 PACCT Board meetings b. 9 b. Numerous (7 at least) b. 14 groups and agencies

Virginia PACCT



Virginia pg. 2

	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
-	1. # of referrals to parent groups	1. No datarecording system	1. 19	1. 11	1. 11
Service	2a. # of new members in groups b. # of parents referred to individual parents	not in place 2a. No data b. No data	2a. 6 b. 5	2a. 9 b. 2	2a. No data b. 2
Service 2	1a. Type of information requested	1a. Referrals/materials	1a. Problem-solving with PACCT staff, venting frustration re: lack of services & access to service, delivery system information	1a. Community-based services, in-home care, respite care, before/after school prgrms.	1a. Names of residential programs, info on a specific topic, system questions, general assistance, after school care
Seri	b. Type of referral made	b. System not in place	b. Support groups, agencies,	b. Same as Quarter 2	b. Same as Quarter 2
••	c. # of calls	c. 6	existing (limited) services c. 21	c. 19	c. 14
Service 3	 1a. # of new groups b. # of new members in statewide organization c. # of members who volunteer d. # of active subcommittees 	1a. 0 b. 0 c. N/A d. No data	1a. 5 b. 2-30 c. N/A d. 4 (Conference, Legislative,	1a. 7 b. 0-25 c. N/A d. 4 (Same as Quarter 2)	1a. No data b. 0-20 c. N/A d. 4 (Same as Quarter 2)
Ser	2. # of Board meetings	2. 2	Budget, Publicity) 2. No data	2. 3	2. 3
Service 4	 # of staff visits to local groups # of newsletters distributed Geographic dispersion PACCT will inform groups restate grants and services 	1. 0 2a. 0 b. Not applicable 3. 3 requests for technical assistance and/or CASSP funds	1. 19 (at least) 2a. 1159 b. Statewide 3. 4 requests for technical assistance (structure, incorporating, publicity,	1. 12 (at least) 2a. 1520 b. Statewide 3. 9 requests for technical assistanceseveral groups received CASSP funds	1. 3 2a. 1790 b. Statewide 3. VAMI workshop, support group materials plus Taking Charge
Š	4. Informal connections made between support groups	4. Yes	developing literature, etc.) 4. Yes	4. Yes	4. Yes



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Virginia pg. 3

	Evaluation Indicators	Ouarter 1	Ouarter 2	Ouarter 3	Ouarter 4
e N	activities, legislative services		1a. All newsletters feature legislative information b. 4	1a. All newsletters b. 1; the Children's Legislative Network (a coalition of 9 organizations)	1a. Same as Quarter 2 b. 4
Servic		2. 0 3. Legislation discussed at 2 Board meetings	plus legislative updates & copies of PACCT Bulletin	1520 PACCT newsletters plus legislative updates & copies of PACCT Bulletin Numerous	2. 1790 PACCT newsletters plus legislative updates & copies of PACCT Bulletin 3. Numerous
Service 6	Activities to encourage participation of urban blacks and rural poor in parent support network	1. Nothing done this quarter	1. Support group in Roanoke was started; letters were sent to Richmond Public Schools to recruit parents whose children were in ED programs	1. 10% of parents who received letters through Richmond Public Schools responded & were invited to attend hearings; PACCT offered financial assistance to persons wanting to attend conferences featuring PACCT workshops; one new PACCT Board member is black	1. PACCT working in Henrico & Richmond to get groups started, 3 new parents given scholarships to attend VAMI/PACCT workshop, effort to increase minority staff and Board members





Hypothesis/Methodology

The research design was developed to carefully document the issues arising during the process of establishing a statewide parent organization. Understanding these issues will contribute to our knowledge about the supports needed by parent organizations to extend their services to greater geographic areas and a greater variety of parents. The evaluation involved case studies of each statewide parent organization demonstration project and analysis of certain variables across all projects.

Two general research questions guided the analysis of the data:

- 1. Did the five parent organizations attain the goals identified in their individual proposals? Did the five parent organizations develop the capacities and deliver the services outlined in the project objectives? and
- 2. What issues and barriers impeded implementation of a statewide parent organization? What resources and supports are needed to facilitate effective implementation of these organizations?

Several methods of data collection were employed in this study. Because conditions and plans were unique to each state, qualitative methods were most appropriate. However, quantitative data were collected wherever possible. The following sources of data were used:

- 1. Quarterly reports with narrative descriptions of the implementation process and of activities;
- 2. A set of seven common data elements collected from each state for the month prior to beginning the organization effort and for the last month of the project;
- 3. Regular telephone contacts with staff of each parent organization; and
- 4. A site visit including unstructured observation and a structured (taped) interview with principal staff and related professionals.

Results

1. Did the five parent organizations attain the goals identified in their individual proposals? Did they develop the capacities and deliver the services outlined in the project objectives?

Each parent organization was responsible for developing and implementing a plan for evaluating their activities and outcomes. Technical assistance was provided in developing these evaluation plans and data regarding these plans was to be reported quarterly. Thus, two sets of data are relevant to the first research question. The first set of data is based on the *individual evaluation plans* developed for each state and exhibited in the grids. The second set of data is derived from the *pre- and post-measurement of common data elements*.

The individual evaluation plans were re-ordered so that the indicators reflect the three capacities and six services outlined in the objectives for the projects. By reading each grid horizontally, the progress of the parent organization can be followed over the year. By comparing grids, it is apparent that the activities and indicators have some common elements, but are unique to each state for the most part.



The common set of data elements collected before and after the demonstration project comprise the second set of data examining the effectiveness of the statewide parent organizations. These data elements were selected because of their ready availability and relevance to the intent of the demonstration project. These data are reported in Table 1.

The following is a summary of the evaluation findings based on these common elements:

Capacity 1: Two way communication with parents

Two states used existing toll-free lines (Montana and Minnesota). One state coordinated efforts with a "warm line" run by a different organization (Hawaii). Wisconsin installed a toll-free line as a result of the demonstration project; Virginia installed a regular telephone line. In each state, telephone calls to the statewide parent organization increased over the four quarters of the project. The use of the "warm line" proved less than successful in Hawaii. Calls most frequently came directly to county coordinators as a result of their outreach efforts and parent calls to the state office were referred to appropriate county coordinators. Although Virginia received many phone calls, it is unclear how many parents were discouraged from calling by the lack of a toll-free number. The number of parents who did call collect is unknown.

Telephone calls and newsletters also proved to be an important avenue for communicating with professionals. In some states, half the phone calls were from professionals seeking information.

Capacity 2: A resource service

All states but Hawaii and Wisconsin had a resource center in place at the beginning of the demonstration grant. All states added resources over the year and offered these to parents and professionals. The most common type of resource added was print materials--primarily books. Although a few projects bought video or audio tapes, project directors complained that there were few appropriate resources in these formats. Several projects (Hawaii, Wisconsin, Virginia) reported slight interest on the part of parents and professionals in borrowing resources. In Hawaii, key resource materials were placed in the public library on each of the islands to be more accessible to parents. Montana reported heavy use of print resources (as high as 40 requests per month), which is primarily due to the isolated rural nature of the state. Print materials can be easily mailed to persons in sparsely populated areas. All demonstration projects reported that a few resources were very pepular; all tried to obtain copies of Taking Charge for parents. Wisconsin reported that short flyers or brochures on topics of interest were more effective than longer print documents. Minnesota distributed many copies of their publication A Guidebook for Parents of Children with Emotional Disorders.



Table 1
Results of Pre- and Post- measurement of Common Data Elements

	МО	NTANA	WISCONSIN		HAWAII		MINNESOTA		VIRGINIA	
	9/88	9/89	9/88	9/89	9/88	9/89	9/88	9/89	9/88	9/89
# of entries on mailing list	1071	1650	1938	2404	300	880	270	2102	899	1700
# of parent groups	20	21 (2 EBD, 19 mixed disability)	10	9	2	. 5	2	7	5	19
# of group participants	Average: 7 Range: 4-20	Average: 7 Range: 4-20	131	164	22	25	14	42	appro x.	approx.
# of phone calis/month	163	203 (45 from EBD)	0•	23	60	not available	18	approx.	2	65
# of print resources	2000	2000+ 35 ED books	57	241	31	120	8	23	approx.	approx. 525
# of video resources	51	6 video + 5 audio for ED	2	5	5	3	1	3	40	appr o x. 48
# of request for print resources	30-50	15 from ED	0*	15	7	2	Data no kept in	t this form	8	3
# of request for video	15-20	0 (all 6 videos reserved for Oct.)	0*	0	3	2	no data	18	20	4

^{*}office opened 11/1/88

Capacity 3: Ability to maintain ties with diverse groups

All demonstration projects published newsletters and considered this an important avenue for communicating with a wide variety of parents, particularly those not interested in attending a support group. The number of names on the mailing lists increased dramatically over the year. Several projects developed brochures or flyers (Minnesota, Montana, Virginia, Wisconsin) for disseminating information about the statewide parent organization and its services. Montana developed a wall poster with post cards that could be removed and returned. All project directors reported being involved in meetings with various coalitions, task forces and advisory committees throughout the year.

Service 1: Refer parents to existing parent groups

All projects made efforts to link parents to support groups in their area. In most states, these requests were low at the beginning of the year and grew as the statewide parent organization became known. Some requests were from professionals who were looking for parent support groups for clients. Requests for referral to parent support groups were limited by the lack of availability of such groups in most areas. In addition, some project directors also referred parents to other parents who had agreed to receive such calls. This proved to be a useful parent-to-parent support mechanism in rural areas. Project directors noted that the parent had to agree to receive the call and had to be out of crisis themselves in order to be of service. In some cases, parents were referred directly to the leader of the closest parent support group; this person often provided individual support to parents.

Service 2: Direct parents to existing referral agencies

All project directors reported frustration with this task. In Minnesota and Montana, the statewide parent organization was considered by parents and professionals to be the best information and referral agency because the organization was most knowledgeable about resources and services. This position was stressful for the parent organization, particularly considering their level of funding. Other projects were successful in using existing information and referral services to answer most parents' questions about available resources. All project directors expressed frustration with the lack of services to which parents could be referred. In some cases, project directors also reported a precarious balance between giving parents accurate information about a particular agency and alienating the staff of the agency.

Service 3: Strengthen the network of parents and parent organizations in the state

Project directors used several approaches to communicate across the state with parents, parent support group leaders, and other parent organizations. In addition to newsletters, project directors often met with parent support group leaders, in groups and individually. In Wisconsin, parent support group leaders met for leadership training. Parents from different parts of the state often convened at conferences, which occurred at the regional conferences in Wisconsin and the state conference in Hawaii.



Service 4: Provide technical assistance to parent groups

For the most part, technical assistance was focused on assisting interested parents in organizing and establishing new groups. Project directors reported that this required a lot of time and persistence. The first few meetings of a new support group often have very low attendance and the project directors had to provide a lot of moral support to the person initiating the group. Often groups die out after the first few meetings and this is demoralizing to all involved. The project director in Virginia reported that she attended at least the first three meetings of a new group and spent time with the group leader outside of the meetings. Most states have one or two groups that are very strong and a number of smaller groups that are often on the edge of dissolving. Most of these smaller groups have four or five core members. Several states (Wisconsin, Virginia, Hawaii) had packets of resource materials for starting new groups that were given to interested parents. Wisconsin provides a stipend (\$200) to assist in group development. Virginia CASSP also makes small grants available to new groups.

Service 5: Develop or enhance a statewide parent organizational structure

Wisconsin, Virginia, and Hawaii have a functioning statewide parent organization that is specifically dedicated to parents of children with emotional disorders. Wisconsin and Virginia have strong and active executive boards, good working relationships with affiliated groups, a part-time paid staff member, and office space. Hawaii Families As Allies has a small group of dedicated parents who form the executive committee, no paid staff and the added difficulty of the expense of bringing parents together from neighboring islands.

Montana and Minnesota do not currently have separate statewide organizations solely addressing the needs of parents whose children have emotional disorders. Montana has incorporated these parents into the umbrella disability organization (PLUK) and has no immediate plans to start a separate group. Given the rural nature of the state and the sparse population, this strategy seems to be appropriate and effective. PLUK staff continue to seek active volunteers among parents of children with emotional disorders. In Minnesota, the plan was to establish a statewide parent group that would become a member of the PACER coalition. Development of an advisory committee has taken longer than anticipated and active leadership has not yet emerged.

All project directors have commented on the difficulty of identifying parent volunteers who have the time, energy and resources to be involved in the statewide parent organization. The difficulty in assuming leadership positions is at least partly due to the stigma attached to being the parent of a child with an emotional disorder. Some parents have refused to speak publicly in their own communities for fear of embarrassing their children. Adoptive parents seem to be the most likely to come forward and participate in organizing activities. In addition to stigma, the lack of services and crisis nature of the disorder keep some parents from being more active. Projects have tried various strategies for encouraging parents to become involved at the state level. Examples of these strategies are the Parent Empowerment Training in Hawaii, the regional conferences in Wisconsin, and the workshops sponsored by Virginia PACCT.



Service 6: Provide special outreach to underserved groups

Demonstration projects have reported the least success in this area. Each organization made some effort to reach out to minority parents or low income parents with varying success. Wisconsin offers scholarships to their regional conferences and received thirteen requests for their most recent conference. Montana has been successful in outreach to the Crow Reservation and conducted a workshop for the home/school coordinators who work with the Indian reservations. Virginia has been successful in recruiting a minority board member and is working to identify a minority parent for the staff position. Hawaii has been the most successful in attracting parents of all cultural and ethnic groups and income levels to their support groups and statewide parent organization. This is partly due to the demographics of the state and to their personal approach. In some areas, county coordinators have not tried to establish parent support groups, but made individual contacts to encourage and develop friendships and supportive networks among parents.

2. What issues and barriers impede implementation of a statewide parent organization? What resources and supports are needed to facilitate effective implementation of these organizations?

The conceptual framework for studying the implementation process is adapted from the framework developed by Van Meter & Van Horn (1975). This framework examines components of six general areas and posits that each can hinder or contribute to successful implementation.

- 1. Characteristics of the proposal. For example, how clear and specific were the parameters of the proposed statewide organization? How well were these parameters understood? How much change was required?
- 2. The resources available. What monetary and in-kind resources became available during the year for this proposal? Who provided these resources?
- 3. The characteristics of the primary implementing agency. For example, what is the size, orientation and stability of the organization responsible for implementing the statewide parent network?
- 4. The characteristics of the individual primarily responsible for implementing the statewide parent network. What was this individual's background, power base, personal resources, etc?
- 5. Interorganizational relationships. How strong were relationships with other important agencies? What needed to be done to ensure their cooperation?
- 6. Social, political and economic conditions. What is the economic condition of the community and state? Were there social or political issues that might intervene in implementation efforts?

Using primarily qualitative data, each of these areas will be examined. The presentation of results in this report will be in summary form. More detailed examination of conditions in specific states will be published in monograph form at a later date.



- 1. Characteristics of the proposal. All of the proposals were ambitious and required a major development effort. In cases in which the project director had also written the grant, fewer modifications were required. In addition, fiscal agents that were knowledgeable about the proposal were also more likely to be supportive during the year.
- Projects in CASSP states received support from their CASSP offices. In Wisconsin and Hawaii, the CASSP grants were in the fifth and final year, so support was not available after the demonstration project ended. Wisconsin, Virginia and Hawaii all received in-kind support from CASSP, including travel, newsletter printing and mailing. The fact that Montana and Minnesota did not have a CASSP grant meant that these states had to look elsewhere for support. In both cases, little interest or support was evidenced from state mental health staff. The Montana project worked well with a university and acquired contributions from other organizations in printing materials. All demonstration projects are experiencing difficulty in obtaining funds to sustain the statewide parent organization. Resources were most needed to pay staff, telephone bills and travel.
- 3. The characteristics of the primary implementing agency. The demonstration projects in Montana and Minnesota were implemented by large, mixed disability advocacy organizations. In both cases, no funds had been available for services specific to parents of children with emotional disorders prior to the demonstration project. Currently, both organizations are very strong and well-known. Wisconsin had a fairly well-developed statewide parent organization before the demonstration project started and received support from their fiscal agent--the state protection and advocacy agency. The parent organizations in Hawaii and Virginia were less well-established. Virginia received good support from CASSP staff and also benefitted from a strong relationship with the State Mental Health Association. Hawaii Families As Allies received considerable monetary support from the CASSP office, but was less involved with their fiscal agent.
- The characteristics of the individual primarily responsible for implementing the statewide parent organization. Each demonstration project was led by a paid staff person who was the parent of a child with a serious emotional disorder. The only exception was Hawaii, in which the lead staff person was salaried by CASSP and not the parent of a child with an emotional disorder. For most of the year. project efforts in Hawaii were devoted to transferring leadership to the parents who comprised the executive board. In each demonstration project, the lead person was key to the success of the project. Project directors worked far in excess of the number of hours for which they were employed. Most project directors attended night meetings, traveled overnight to out-of-town locations, and responded to parent calls on their home telephones. In addition, the personal interests and skills of the project directors influenced the direction of the statewide parent organization. In some projects, the director was more interested in legislative activities and became most involved in this arena. In other projects, the director was most experienced or skilled in support group development or individual case advocacy, which became the focus of the organization.
- 5. Interorganizational relationships. All projects put considerable effort into establishing and maintaining positive relationships with organizations involved with children who have an emotional disorder. Development and maintenance of these relationships was time consuming. Project directors reported that multiple requests for parent representatives were received as soon as the organization



became known. This often placed pressure on the project director to be a member of too many committees because of the difficulty in finding other parents who had the time to be involved in state or local decision-making.

Sometimes turf issues with other organizations were encountered; a range of reactions from state mental health divisions were encountered, from enthusiastic support and involvement to apathy and lack of interest.

6. Social, political and economic conditions. In Montana and Hawaii, geography proved to be one of the greatest barriers to development of the statewide parent organization. In both cases, real geographic barriers and the expense of intrastate travel prevented parents from meeting on a regular basis. Distances posed a difficulty in the other three states, although not as great a barrier.

The commitment of the state mental health division to both children's mental health and parent involvement also proved to be a determining factor in the development of the statewide parent organization. In Virginia and Wisconsin, the existence of a county-based system of funding services greatly increased the parent effort needed to effect funding for children's services.

Specific legislative issues emerged in each state. Wisconsin, Montana, Minnesota and Virginia all witnessed development and passage of a bill related to mental health services for children. In all cases, this legislative activity consumed much of the parent organization's energy.

In general, the primary barriers to development of statewide parent organizations are: (1) lack of resources to support organizational efforts and sustain the statewide organization; (2) lack of a core group of parent volunteers with the energy to sustain and fully develop the organization; (3) lack of acceptance and support from state and local mental health leaders; and (4) a lack of services for children with emotional disorders, resulting in the parent organization concentrating on case advocacy for members before attending to organizational issues. The results of this evaluation suggest that local groups need two to three years and additional resources (approximately \$30,000 per year) to establish a strong and well-functioning statewide parent organization.



REFERENCE

Van Meter, D.S. and Van Horn, C.E. (1975). The policy implementation process: A conceptual framework. Administration & Society, 6(4), 445-487.



APPENDIX

INVITATION TO BID



Portland State University

RESEARCH AND TRAINING CENTER

A Center for Research and Training to Improve Services for Seriously Emotionally Handicapped Children and Their Families

MEMORANDUM

June 21, 1988

TO:

Parent Organizations, State Mental Health Representatives for Children and Youth (SMHRCY) and Child and Adolescent Service

System Program (CASSP) Project Directors

FROM:

Barbara J. Friesen, Ph.D., Director Portland Research and Training Center

Enclosed you will find a request for proposal for a Statewide Parent Organization Demonstration project. The Research and Training Center will fund up to five twelve month projects at a level of up to \$20,000 each during the coming year (October 1, 1988 to September 30, 1989), depending on the availability of funds. Eligible applicants are parent organizations. The purposes of this project are to stimulate and support the development of model statewide parent organizations, as well as to evaluate the implementation and outcome of these projects. Only one demonstration project will be funded in any given state.

We want this request for proposal to be distributed widely to parent organizations around the country, and we are mailing it to a number of parent organizations and state mental health personnel (see Section V., Selection Process, in the enclosed request for proposal). Please assist us by distributing copies of the enclosed information to parent organizations of which we may not be aware.

Please note that proposals are due at the Research and Training Center by Friday. August 26. 1988 at 5 p.m.

Thank you for your help. If you have any questions about this process, please call me, Nancy Koroloff, or Katie Yoakum (503) 464-4040.



503/464-4040

Portland State University

RESEARCH AND TRAINING CENTER

A Center for Research and Training to Improve Services for Seriously Emotionally Handicapped Children and Their Families

STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT REQUEST FOR PROPOSAL

I. PURPOSE OF THE PROJECT

The overall purpose of this Statewide Parent Organization Demonstration project is to promote the organization of parents of children with serious emotional disabilities for the purposes of giving and receiving support, acquiring information about their children's condition, and learning to become advocates for their own children and on behalf of others.

The Statewide Parent Organization project has two major goals: (1) to stimulate and support the development of model state-wide parent entities that have the capacity to provide technical assistance, information, support, and networking assistance to parents and parent organizations within states; (2) to evaluate the conceptualization, implementation, and outcome of these models in order to inform decision-makers about the most effective approaches to promoting such activity within states.

II. PROJECT ABSTRACT

Through the Families as Allies Project, the Portland Research and Training Center will fund up to five Statewide Parent Organization Demonstration projects for the purpose of developing statewide parent networking and organizational structures during FY 1988-89 (12 months beginning October 1, 1988). Eligible applicants are existing parent organizations that can demonstrate the capacity to fulfill project objectives. Each project will address a common set of expectations, but has flexibility in developing creative approaches to achieving them. Each project will participate in an implementation study designed and carried out by Families as Allies project staff. This study will assess both project implementation (the extent to which the project was carried out as planned, reasons for changes in plans, what worked well, what didn't, and so on), and the outcome, or extent to which each project achieves its objectives.

The results of both the study of implementation and the evaluation of the Statewide Demonstration Projects will be summarized in a monograph. This monograph is intended for use by federal and state decision-makers as well as by parent organizations wishing to start a Statewide Parent Organization. The monograph will be disseminated 1.2tionally.

III. EXPECTATIONS FOR CENTERS

By the end of the project year, each Statewide Parent Organization will need to demonstrate the following capacities:

1. a mechanism for inexpensive, accessible two way communication with parents on a statewide basis.



503/464-4040

- 2. a resource service for the dissemination of print and visual media that is accessible on a low cost basis to parents, professionals and parent groups statewide. If appropriate, this may be achieved through the expansion of an existing resource service to include materials specifically relevant for parents of children with emotional disabilities.
- 3. the ability to develop and maintain ties with diverse groups and individuals throughout the state (this may include services, resources, information and visibility).

These capacities represent the essential framework within which the statewide parent organization or coalition will provide the following services:

- 1. Refer parents to existing parent groups or to individual parents in their geographic area.
- 2. Direct parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.
- 3. Strengthen the network of parents and parent organizations by making a sustained effort to increase formal and informal contacts among individuals and groups.
- 4. Provide technical assistance and support to newly forming or ongoing parent support groups, including "state of the art" information on services for emotional disturbances in children and adolescents, and the range of community based service options required to meet their needs.
- 5. Develop or enhance a statewide parent organizational structure capable of providing information regarding pending legislation, state planning processes, and opportunities for public comment and testimony at relevant legislative and administrative hearings on a timely basis.

It is recognized that the amount of money in this award is not sufficient to build new parent networks where nothing exists. Successful applicants will most likely be those that have the capacities and services identified above at least partially in place. The limited resources provided will need to be supplemented and applicants are encouraged to pursue other sources of support (both monetary and in-kind). Applicants need to describe what is currently in place and how they intend to achieve adequate support for the project.

IV. EVALUATION OF PROJECT OUTCOMES AND IMPLEMENTATION

Successful applicants will be responsible for implementing a plan for evaluating the Project's success in providing the services and capacities outlined in section III. Projects will be expected to submit data and a narrative report on a quarterly basis. Staff from the Research and Training Center will assist with the development of the final evaluation plan and will help Project staff decide how to collect the necessary data. An evaluation specialist will make at least one trip to each project for the purpose of providing technical assistance regarding the evaluation effort.



The proposal should include a statement describing how the Project intends to evaluate increases in its capacity to serve parents of seriously emotionally disturbed children. This section should include a description of any current methods used to collect data and plans to develop or expand this capacity.

The following list contains <u>suggestions</u> of some types of data that Projects may wish to collect regarding services.

- 1. Number of phone calls from parents received, service requested, service provided.
- 2. Number of in-person contacts, service requested, service provided.
- 3. Number of parent requests for information about the service delivery system, referral made.
- 4. Number of requests for technical assistance from newly forming or ongoing parent groups, assistance requested, assistance provided.
- 5. Description of each activity undertaken to increase contacts among parents and parent groups.

Evidence of capacity may be assessed in the following manner:

- 1. Measure the amount of use of 800 or 900 phone numbers if such a system is used. Focus on both number of calls and geographic distribution of calls. Both number and distribution should increase over the year.
- 2. Count the extensiveness and size of the the resource service (number of printed products, number of video and audio tapes) at the beginning of the grant. The number of units of material available through the resource service should increase. Measure the amount of usage, the variety of persons requesting and the geographic dispersal of requests. All three indicators should increase over the year.
- 3. Analyze the number of persons and groups represented on the Project's mailing list. Total number, variety and geographic dispersion should increase over the year.
- 4. Analyze the visibility of the resource service within the state.
 Awareness of resource service should increase over the year.

In addition to the evaluation of activities, research will be done on the process of implementation that occurs with each Project. This research will be designed and conducted by the Portland Research and Training Center in collaboration with the Statewide Parent Organization Demonstration project staff. The studies will carefully examine and document the issues that arise during the process of establishing the statewide parent networks. Data on implementation will be collected through a series of monthly telephone chils with each Project director. Projects will also be asked to submit products of the resource center as well as narrative descriptions of the development process as a part of their quarterly report. The data on implementation will be compared with each Project's evaluation of its success to achieve an overall synthesis of those conditions that seem to lead to successful implementation of a statewide parent network.



V. SELECTION PROCESS

DUE DATE: Proposals are due at the Research and Training Center in

Portland by Friday, August 26, 1988 at 5 p.m.

MAILING

c/o Barbara J. Friesen

ADDRESS:

Statewide Parent Organization Project

Research and Training Center Portland State University

P.O. Box 751 (Street address: 1912 S.W. 6th Ave)

Portland, OR 97207-0751

FOR FURTHER

Call Katie Yoakum, Nancy Koroloff, or Barbara Friesen,

INFORMATION: Families as Allies Project (503) 464-4040.

Invitations to bid have been distributed to potential applicants (parent organizations) including each of the parent organizations in our Parent Organization Directory and additional parent organizations that have indicated an interest in being listed in the Directory. In addition, the Child and Adolescent Service System Program (CASSP) and the State Mental Health Representatives for Children and Youth (SMHRCY) personnel in each state have received information about this opportunity. We will also publish information about this opportunity in the Summer, 1988 issue of our bulletin, Focal Point.

Criteria for selection will include overall content and logic of the proposal, and assessment of feasibility, including current state of development within the state, proposed staffing, and suggested sources of additional resources.

The proposals will be reviewed by Families as Allies staff, and by a review committee composed of parents and professionals.

VI. PROJECT TIMELINES

August 26, 1988 Proposals due by 5 p.m.

September 19, 1988 Projects selected for funding; applicants notified

October 3, 1988 Project funding period begins

November, 1988 Directors of funded projects meet in Portland with

Research & Training Center technical assistance and evaluation staff (R & T Center pays travel, room and

per diem for this visit)

Quarterly (January 9, April 10, and July 10, 1989)

Quarterly reports due to Research & Training Center

September 15, 1989 Final report due

STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT Suggested Outline

I. THE APPLICANT ORGANIZATION

A. BACKGROUND INFORMATION

In this section, provide (a) a brief history of your organization; (b) purpose and mission of the organization; (c) a description of the organizational structure, including affiliations with other organizations or agencies and an organizational chart; (d) type of organization (publicly funded, private non-profit, other); (e) funding sources; and (f) staffing (number and F.T.E. of paid staff, volunteer staff, and other personnel involved in your organization).

B. CURRENT ACTIVITIES AND SERVICES

Include a brief overall description of the activities of the applicant organization, and specifically for parents whose children have serious emotional disorders: (a) describe the purpose, activities and services currently provided to parents whose children have serious emotional disabilities; (b) discuss the nature of current contacts (face-to-face, telephone, mail) with parents whose children have serious emotional disabilities; and (c) indicate the numbers of parents served.

C. RELATIONSHIPS WITH OTHER ORGANIZATIONS

In this section, describe current relationships with other organizations and groups that serve or support families whose children have serious emotional disorders. Also describe other relevant relationships with community, state, or national groups.

II. STATEWIDE PARENT ORGANIZATION PROJECT DESCRIPTION

- A. <u>Project overview</u>. Provide a brief description of the project (up to 150 words).
- B. <u>Statement of purpose</u>. Briefly describe the purpose of the proposed statewide parent organization project, including the need for such an organization in your state.
- C. Objectives, activities and timelines. In this section, address each of the capacities and services outlined in Section III of the invitation to bid through developing your own objectives and action plans.
- D. Staffing and management plan. Describe the duties and background of the personnel who will be involved in implementing this project. Resumes and job descriptions of key personnel should be included in an appendix. The management plan should describe the structure and organization of the project, responsibilities of various project staff members, and how accountability will be assured (to be certain that the project meets its objectives).



- E. Organizational capability and project feasibility. In this section, describe the resources and capabilities of the organization to carry out this project. If current resources available for this project (monetary and in-kind support, technical assistance, and so on) are insufficient, describe how sufficient resources will be obtained.
- F. Budget and budget justification. Include a budget and narrative description of how the funds made available through the Research & Training Center will be used.
- G. Evaluation plan. This section should describe the plan for evaluating the Project's success in providing the services and and developing the capacities listed in section III. It should also include a description of the methods currently used to collect and summarize data.

Research & Training Center Portland State University P.O. Box 751 Portland, OR 97207-0751

Statewide Parent Organization Demonstration Project Final Report

EVALUATION FORM

1.	Who used the final report? (Check all that apply.)								
	Parent	E	ducator	Ch	ild Welfare Worker				
	Juvenile Justic	Juvenile Justice WorkerMental Health Professional							
	Other (Please Spe	cify)		<u> </u>					
2.	Please describe th	e purpose(s)	for which y	ou used the	he report:	•			
3.	Would you recom	mend use of	the report	to others?	(Circle one)	,			
	Definitely	Maybe	Condition	onally	Under No Circumstance	:S			
	Comments:								
,	Overall, I thought	the report w	as: (Circle	one)					
	Excellent	Aver	age	Poor					
	Comments:			- <u></u>					
5.	Please offer sugge report:	stions for the	e improven	ent of sub	esequent editions of this				
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